

Social inclusion and a full life is still a challenge

How do we help our children and adults to belong – to have friends, relationships and to be fully part of the community?

The theme of the first two feature articles in this issue is the challenge of full social inclusion and full participation in life as a child and as an adult. The first article focuses on sexuality and sex education, the second on 'circles of friends' in primary school but both are tackling the issue of how to enable our children and young people to have full lives and to really feel that they belong in the social settings they are in. We have made great strides in including children in education, in adult living and in work – we no longer shut folks away in institutions for the 'handicapped'. We are getting quite confident in meeting educational and practical needs, therefore giving young people with Down syndrome the skills they need to be as independent as possible in their everyday lives at school, at home and at work. However, social inclusion is still a challenge and many teenagers and adults are isolated – they do not have many friends or leisure opportunities outside school or college or workplace. Even in inclusive schools, children and teenagers with Down syndrome may not have real friends – some have many friends and are fully included but some are quite isolated, with teachers asking for advice on how to improve their social inclusion.

Do not leave it to chance

Both parents and teachers need to acknowledge that social inclusion cannot be left to chance. It usually needs to be thought about and explicitly planned for. This is well illustrated in the 'circle of friends' article. Issues (problems) started to arise quite quickly for a child with Down syndrome starting school in reception class. She was small,

pretty and had limited spoken language. The other children wanted to 'mother' and 'smother' her – they did want to play with her, she was socially included but their behaviour towards was inappropriate and she started to show her displeasure in the only way she could. In many schools, the situation would have deteriorated rapidly with her negative behaviour (pushing, biting) seen as a 'behaviour problem' due to having Down syndrome and she would have been on the way to exclusion. Fortunately, the teachers and support team were more perceptive and realised that the other children did not know how to play with her and she could not tell them how she felt.

Peers need support and information

The 'circle of friends' approach provided a chance to talk with the class about disability and about how the particular child might feel. This enabled them to change their behaviour and become real friends over several years – but the support of staff through 'circles of friends' meeting continued to be sure that they could all work together to ensure the child continued to be fully included. In our experience, there is a wealth of goodwill among mainstream peers but they are not always sure how to build effective relationships with a child with a disability without adult support.

Teenage and adult relationships

Close friendships raise another set of issues where education and support are equally important but this time it is education for the person with Down syndrome. Both parents and teachers worry about the sexual

development of teenagers with Down syndrome; How will they cope? Will they behave inappropriately? Can they manage close and sexual relationships? Both research and personal experience shows that most young people with Down syndrome are sensitive and competent when it comes to sexual matters. Readers may already know that I have an adult daughter who has had a close, loving, physical, and successful relationship with a partner who also happened to have Down syndrome.^[1]

Letting go, respect and trust

There are some fundamental issues at stake here and we need to challenge ourselves whether parents or professionals – do we really accept the right of the child or student with Down syndrome to be a fully whole person? Or, are we actually thinking of them as always a child – never fully an adult? Our subtle underlying assumptions will affect all our interactions and expectations for the person at home and in the classroom.

Most adults with Down syndrome want a life of their own, privacy, independence, interesting social lives, meaningful work, friends and sometimes partners. Most can manage their lives as competently as the rest of us if treated like adults, given respect, encouraged to make decisions and be in control of their lives, with maybe a little more support in the background but do we not all depend on support from friends and family into adult life?

Editor

1. Buckley, S. (2000). *Living with Down Syndrome*. Portsmouth: The Down Syndrome Educational Trust. [Online] Available: <http://www.down-syndrome.info/library/dsii/01/01/DSii-01-01-EN-GB.htm>